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ABSTRACT

Psychological and social dimensions of serious illness among children are discussed in this manual for child care personnel in day care homes and centers. Parental feelings and reactions such as denial, anger, guilt, blaming, searching for a cure, more anger and acceptance are outlined. The feelings and attitudes of the preschool child, elementary school child and teenager are indicated. The role of the careperson is defined in terms of thinking seriously about one's own attitudes and feelings, being aware of and dealing with the attitudes and actions of other children, the day-to-day management of the seriously ill child within the day home or center setting, helping the intermittently hospitalized child, and consulting with parents on continuity between school, home and hospital. An appendix lists serious diseases and briefly describes them. (A slide/sound presentation and pamphlets were produced in conjunction with this manual.) (RH)

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THE SERIOUSLY ILL CHILD

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Module V

THE SERIOUSLY ILL CHILD

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Module V

THE SERIOUSLY ILL CHILD

In years past many children died in infancy; numerous contagious diseases claimed the lives of young children. Immunizations now protect our children from most of these diseases. Other diseases which threaten the lives of children, such as leukemia, cystic fibrosis, and diabetes, can be temporarily arrested or controlled. Problems such as heart conditions, kidney diseases, and other physical differences, can be temporarily or permanently corrected. In such cases, however, extended hospitalization which strongly affects the child and the child's family is often required. And the possibility, even the probability, of an early death still confronts some children and their families, despite the determined efforts of the modern medical profession.

Each child who suffers from a life-threatening illness deserves the opportunity to live as normal a life as possible. This manual is designed to provide you, the day-home mother, the child-care worker, or other adult responsible for the care of children, with help in providing security and comfort to the seriously ill child in your care and to his or her parents. The feelings and attitudes that often arise in the seriously ill child and in the child's family will be described in general.

Just as each child is unique, each disease or problem area is also unique. Therefore, you will want to find out as much as possible about the child from the parents and from other adults who work with the child (like the doctor or therapist), so that you can provide the most appropriate care and comfort.

Children who are dying are often referred to as "terminal" by medical personnel. But since many diseases are cured when new treatments are discovered, and because many children who are seriously ill have remissions or temporary recoveries from their illnesses, in this manual the child is referred to as seriously ill.

Usually you, the adult careperson, will not be responsible for the care of the child during the last period of his or her life. By that time, the child is usually hospitalized and under the care of medical personnel. However, someday you may be asked whether you are willing to take care of a seriously ill child in a day-care situation. Or you may find at some time that one of the children already in your care has been diagnosed as having a terminal illness.

What can a careperson expect when caring for and teaching a seriously ill child? Each case is different. Only general rules and information can be given. For the most part, you will have to depend upon your basic common sense combined with your sensitivity to the needs of the parent and the child. Working with a seriously ill child while knowing the child is not expected to live, is a difficult and heart-rending task. Surpirsingly, however, the experience can be a period of growth for you as you develop greater insight into your own feelings and the feelings and needs of others.

You are part of a team struggling to extend the child's life and keep him him or her as emotionally happy and secure as possible during the months or years of illness. You will need to understand the attitudes and feelings of others: the child and his or her family. The child's understanding of death varies not only in relation to his or her age, but also in relation to the attitudes and feelings of those around the child. Understanding your own human attitudes is also helpful. It is normal to be uneasy about sickness and death. But it is also possible to learn to deal with the fact of death.

THE FAMILY

Understanding the feelings and reactions of the parent(s) of a child who is seriously ill and dying is critical. Attitudes and reactions within the family influence the child and the way the child deals with his or her feelings. In some cases, you might be the first person to suspect that a child in your care has a medical problem. You may have been the one who suggested to the parents that their child see the doctor who identified the illness. Or the parents may have brought a child who has been ill for a long time to the day-care center or the day home so that the child can live and grow as long as possible with other children of the same age. In any case, you will want to work closely with the parents, and understand their needs and reactions as well as the needs of the child. By working together as a team, you can help the child live as normal and happy a life as possible.

General Considerations

Understanding parents' reactions to their child's serious illness is an important first step for anyone who takes care of the child. The feelings and attitudes of parents, their acceptance of the child's illness, the way they act, and the things they say, will have a strong influence on the child. Remember that each parent is an individual with his or her own concerns and ideas about the child's illness and necessary care. You can help enormously by being aware of and accepting these feelings and by listening to the parents as much as possible.

Besides considering the parents' feelings, try to remember that they have other obligations and responsibilities. If you feel they are neglecting their ill child, try to consider the other demands upon their time. Perhaps the mother works. There may be only one parent in the family. Money is very probably a strain. For instance, some children with cystic fibrosis take more than 40 pills a day: the cost of drugs, equipment, clinic, laboratory, physician fees, and hospitalization can run up to $5,000 or more a year.

Spending time with other brothers and sisters often becomes one of the biggest problems for these parents. Brothers and sisters of seriously ill children often have emotional problems of their own. They may show anger, embarrassment, guilt, and grief--or even worse, they may hide these feelings. Parents may have their hands full trying to balance their duties and divide their time fairly. And parents, like anyone else, must have some time for themselves and each other.

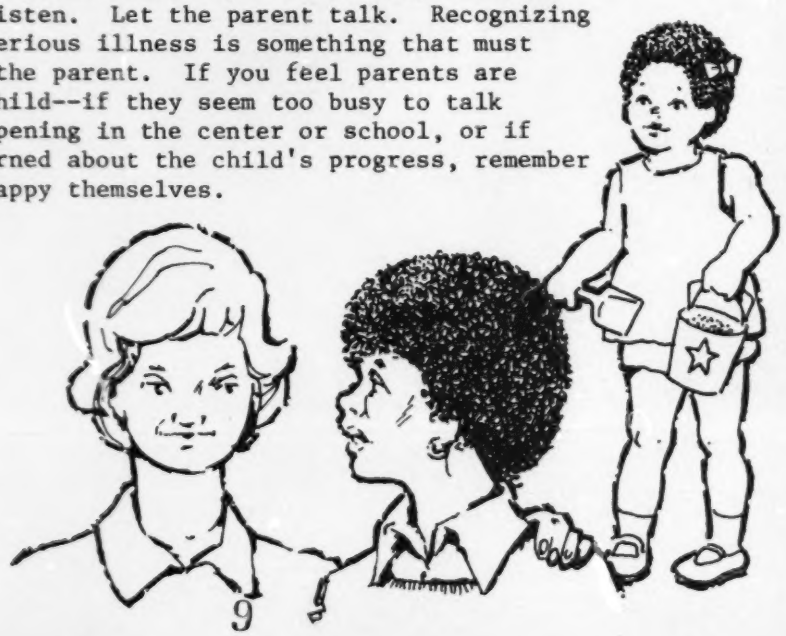
Parent Reactions

Certain stages of feelings occur when people are faced with death and loss. The following stages of feelings are not steps through which parents or others close to the child automatically progress in an orderly fashion, solving each problem clearly and distinctly. It is not at all unusual for a parent to go back and forth between different stages of reactions. This is particularly true when a child has been diagnosed by one physician as seriously ill and dying and then diagnosed by another in a more hopeful light. In many instances, a child may have a temporary remission of symptoms. When the child becomes ill again, the parents have to face the same problems and feelings once more, often with reduced emotional resources.

1. Denial

Of course, parents wish that their child were healthy. Many parents try desperately to ignore the problem. It may seem strange, but in some cases the parents are so upset that they ignore or reject the child. They do this not because they are mean or unfeeling, but because they have no way of dealing with the hurt and helplessness they feel when they think of their child. "It was like a nightmare," "I couldn't believe it," "I felt it must be happening to someone else," are common reactions from parents.

In working with parents who have just discovered that their child's illness is terminal, it is not your place to tell the parent to accept the situation. Neither should you try to explain it to them. This is the role of their physician. The greatest service you as a careperson can do is to simply listen. Let the parent talk. Recognizing and accepting a serious illness is something that must come from within the parent. If you feel parents are rejecting their child--if they seem too busy to talk about what is happening in the center or school, or if they seem unconcerned about the child's progress, remember that they are unhappy themselves.



2. Anger

When parents realize that their child's problem is serious, and will not disappear, and that the child may die, they may feel angry. "Why does this have to happen to my child?" "Why does this have to happen to me?" As they look around at other healthy, growing children, and realize that their child is not healthy and will not grow to be an adult, it is natural for them to resent other children and to feel angry. Anger is not limited to the illness or to other children. Their anger may be directed toward the doctor or toward another person who first told them of the illness, or to the medical personnel taking care of the child. They may feel angry with you, the adult caregiver, as well. Their frustration and anger will spill over on anyone who is around. Try to listen and not take their anger or hostility personally. Remember that parents are angry because they care very deeply about their child. If they did not care, they would not get angry. Even if they are angry with you at the moment, it is probably only because you are there. They are hurt and upset, and anger is their reaction.

What can you do? Remain calm and do not let your feelings be hurt. Parents who are concerned with their problems and are trying to do the best they can for their child do not have the energy to be concerned with your feelings or anyone else's. Listen with understanding. Sometimes it helps to reflect or restate the parents' feelings to let them know you understand. Focus on the present, the child today, and what he or she can do. Assure the parents that you will work with them and their child, and that together you will help their child live and learn as normally as possible. Encourage them to visit the classroom or center, and to see their child. Tell them you would welcome suggestions for better ways of working with the child. Above all, don't condemn the parent.

3. Guilt

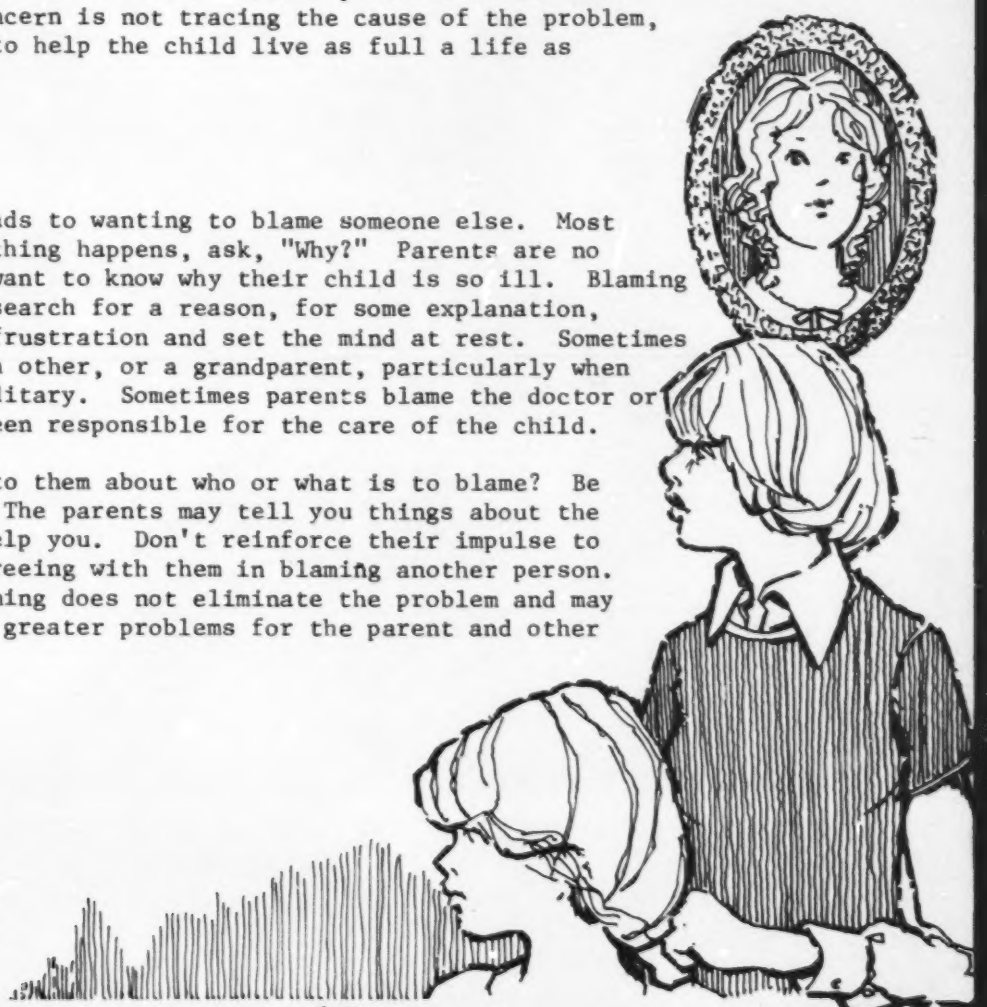
Sometimes parents feel guilty, as if they were to blame for their child's illness. Some children have diseases thought to be hereditary conditions. Frequently parents, especially mothers, feel that they should have prevented the child's illness. They may feel this way even though the cause of the condition is unknown, or even though the doctor has told them that they did not cause the problem. In many cases the causes of serious conditions are not known; frequently there seem to be multiple possible causes. Nevertheless, a parent will wonder: "Was it something I did while I was pregnant. . ." "Should I have. . .?"

What can you say to parents who feel guilty? Be patient and do not argue with them. It takes a long time for parents to learn to deal with the fact of a seriously ill child. Assure them that you know that they are doing their best for the child, and that the doctors and other medical personnel are doing their best. Listen to the parent and be sure you do not sound as though you blame them for the child's problem. Tell them that your main concern is not tracing the cause of the problem, but finding ways to help the child live as full a life as possible.

4. Blaming

Feeling guilty leads to wanting to blame someone else. Most people, when something happens, ask, "Why?" Parents are no different. They want to know why their child is so ill. Blaming is a part of the search for a reason, for some explanation, anything to ease frustration and set the mind at rest. Sometimes parents blame each other, or a grandparent, particularly when diseases are hereditary. Sometimes parents blame the doctor or others who have been responsible for the care of the child.

How can you talk to them about who or what is to blame? Be ready to listen. The parents may tell you things about the child which can help you. Don't reinforce their impulse to place blame by agreeing with them in blaming another person. Remember that blaming does not eliminate the problem and may ultimately create greater problems for the parent and other family members.



5. Searching

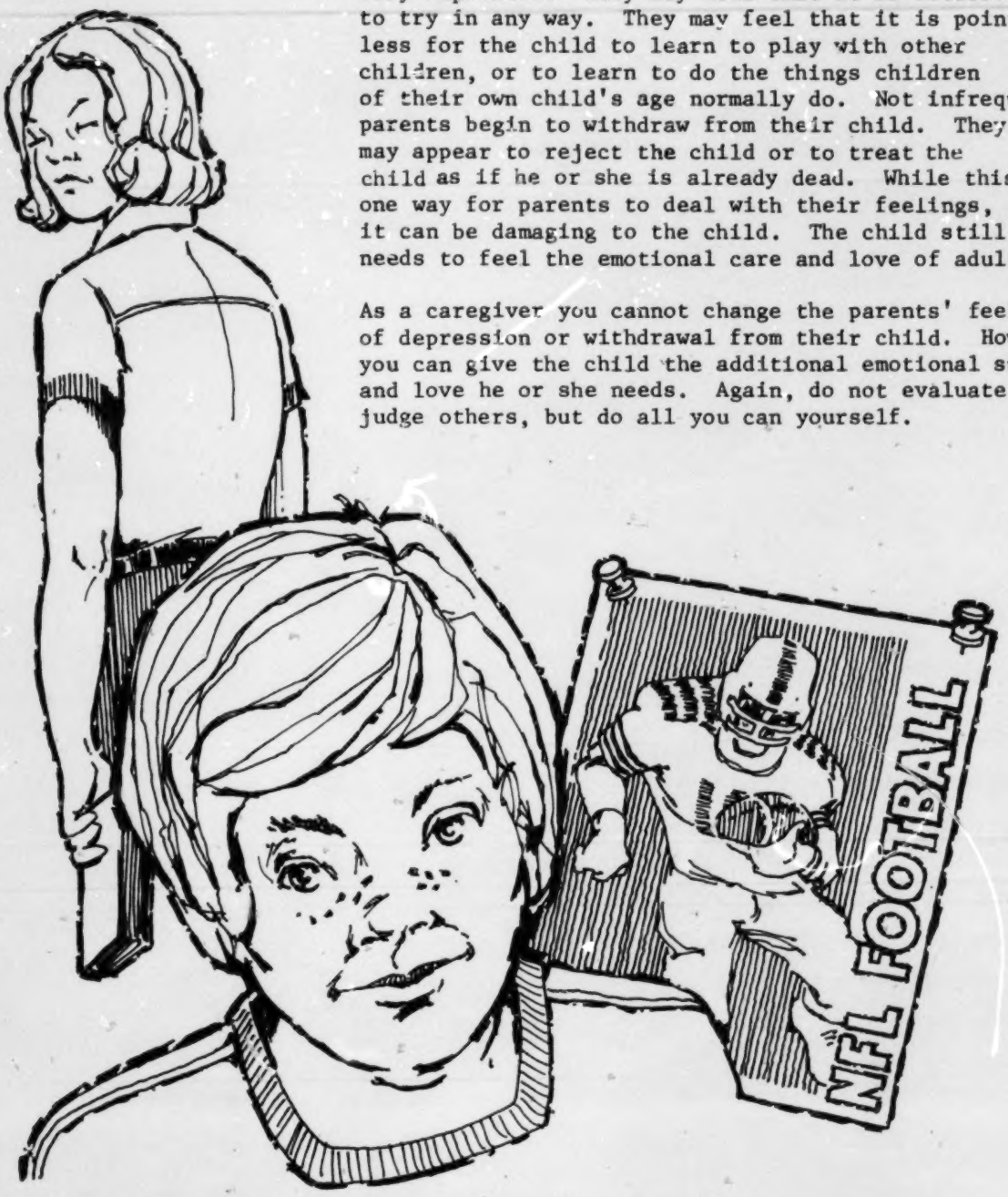
Most parents of children who are seriously ill will look for someone or something that might cure their child. This is normal and reasonable; certainly more than one medical opinion should be sought. New cures or methods of dealing with a seriously ill child are developing all the time. Through searching, parents help relieve some of the feelings of guilt and frustration. It is very important for parents to feel that they have done all that they possibly can to help their child. For some parents, it may seem that if they stop looking for a cure they will be giving up. Sometimes they will go from doctor to doctor trying one new medicine or treatment after another, searching frantically--to the point of exhausting themselves and their finances. Parents desperately want their child to live.

When you talk to parents who are searching for something to make their child well, it is not your place to tell them that there is no magical cure. As a careperson, you do not know all the medical possibilities. What you can say is that until a solution or a cure is discovered you want to help the parents by working with their child in the best possible way. Your goal is to help the child live as full a life as possible.

6. Depression

After parents have begun to accept the fact that their child will not live a normal life and that the diagnosis is correct, they frequently become very depressed. They may feel that it is useless to try in any way. They may feel that it is pointless for the child to learn to play with other children, or to learn to do the things children of their own child's age normally do. Not infrequently parents begin to withdraw from their child. They may appear to reject the child or to treat the child as if he or she is already dead. While this is one way for parents to deal with their feelings, it can be damaging to the child. The child still needs to feel the emotional care and love of adults.

As a caregiver you cannot change the parents' feelings of depression or withdrawal from their child. However, you can give the child the additional emotional support and love he or she needs. Again, do not evaluate or judge others, but do all you can yourself.



When a child has an illness which causes him or her to become progressively less attractive or even repulsive to others, it is sometimes difficult for parents, as well as caregivers, not to show some signs of rejection. But remember, the child still has the same emotional needs as other children.

As they become more ill, some children may regress in their behavior or in their ability to take care of themselves. The child may lose the ability to control his or her bowels, for example. Although this may mean extra effort for you, the caregiver, as long as it is possible to keep the child with other children in a normal setting, it is important to do so. Even though the child may have a short life, he or she deserves to have as happy and normal a life as possible. Changing a few extra diapers or pants is a small thing in comparison to allowing the child to remain with others. And for most people accustomed to taking care of children, the unpleasant duties are all in a day's work.

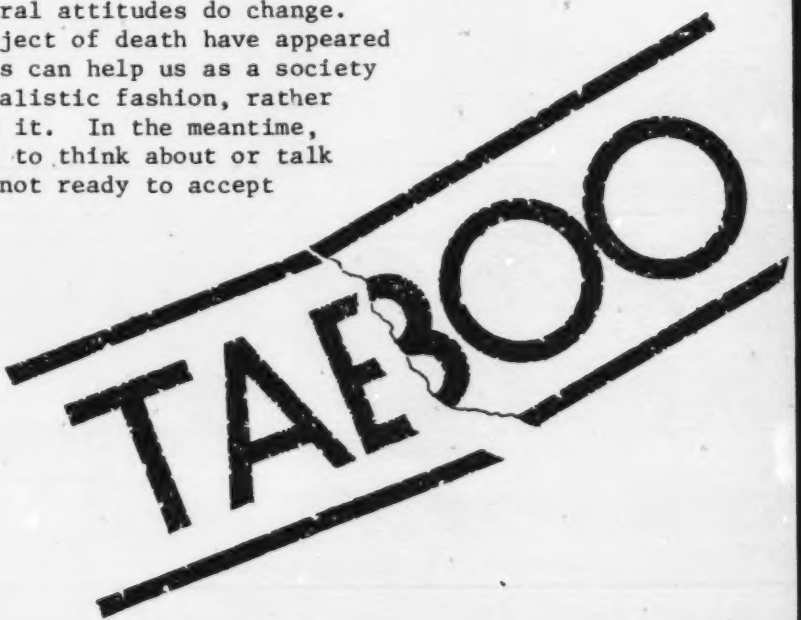
Parents, especially mothers, need the help of the day-home or child-care-center people. The full-time continuous care of a child who is dying is emotionally draining for the adults in the family. Mothers desperately need "relief time" to be with their other children and to pursue normal adult activities. By caring for their child for a part of the day, you, the caregiver, are helping not only the child, but the parent and other family members as well.

7. And more anger

Sometimes children with serious illnesses have remissions and appear to be getting better. The parents may have reason to believe that their child will be okay and will recover. In many cases the medical personnel do not know for certain and they too may feel that the child will recover. When this happens the parents are thrown into an emotional high and have positive hopes for a normal future. Unfortunately, however, the remission of a serious disease is often temporary. The parents cycle through the feelings of frustration and anger again. Once more they must struggle with their feelings about death and their feelings about the child.

8. Acceptance

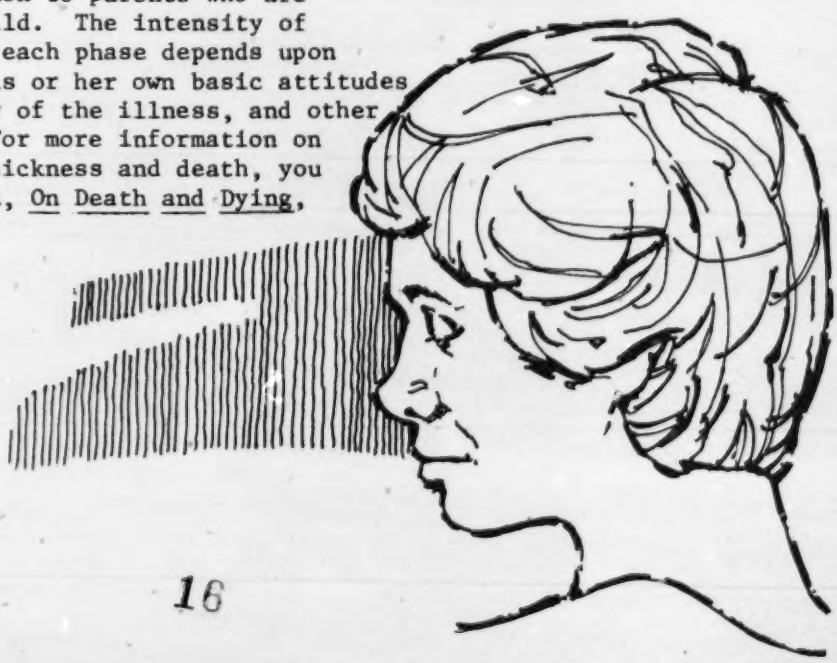
What does it mean to accept the impending death of a child? This is a nearly impossible task for parents. Frequently full acceptance does not really occur until years after the child has died. "Acceptance" may mean accepting the child as he or she is, and enjoying the moment, and yet realizing that the child will not live. Acceptance also means accepting the finality of death--and a part of this is recognizing and accepting the inevitability of one's own death. In our culture, until very recently, we have not dealt with, or even discussed, death. It is treated almost as a taboo subject, ignored as if it were not a fact for each of us. Sometimes it seems as if we are barely allowed to mourn the death of a dearly loved family member, and are not allowed to share our grief with others. But cultural attitudes do change. Books and articles on the subject of death have appeared in recent years, which perhaps can help us as a society learn to accept death in a realistic fashion, rather than trying to ignore or deny it. In the meantime, most people still do not like to think about or talk about death because they are not ready to accept their own mortality.



In terms of the child, what does acceptance mean? Accepting the child means knowing what he or she can do and being proud of each accomplishment. It also means being aware of what he or she cannot do and giving help when needed. Acceptance means giving the child work to do which helps the child feel independent, but not so much work that the child is frightened or defeated. The child, like other children, still learns from mistakes. It means loving the child and giving the love and support needed by all children, but not trying to shelter the child from all the little hurts children normally experience. Finally, acceptance means loving and helping the child just as if he or she were going to live a normal life and making the child's days as happy and pleasant as possible. Acceptance does not mean overprotection, which is usually an attempt to ease our own guilt and fear rather than to help the child.

Acceptance of this type, treating the child who is seriously ill in the same way you would treat other children, is the greatest gift you can give to the child and to the parents. Any time you talk with the parents, try to tell them about things their child can do and the ways in which he or she is enjoying each day. By showing them your willingness to join in the child's life and your acceptance of the child and his or her illness, you can help the seriously ill child.

The above stages are common to parents who are facing the death of a child. The intensity of feeling displayed during each phase depends upon the individual parent, his or her own basic attitudes and beliefs, the severity of the illness, and other family considerations. For more information on individual responses to sickness and death, you may want to read the book, On Death and Dying, by Elisabeth Kubler-Ross.



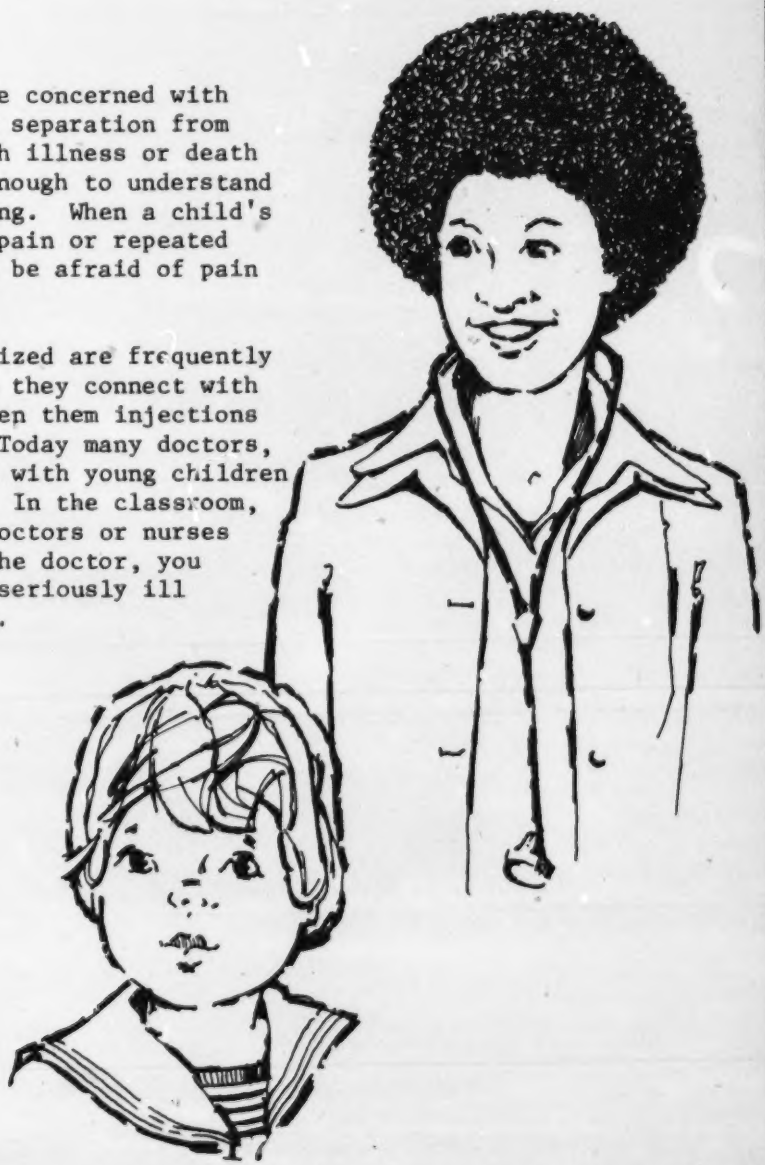
THE CHILD

Feelings and attitudes of the seriously ill child will vary in relation to the age of the child, the type of illness, the child's knowledge of his or her illness, and the reactions of those around the child. At all ages children reflect the feelings and attitudes of others, particularly their parents, in regard to illness. Children who have been hospitalized often or for long periods may dislike and fear doctors and fear pain. You will have to be alert to the child's particular world, just as you are alert to the individual needs of each and every child in your care. But some background knowledge of how children of different ages are likely to respond to their illness and possible death will be of help to you.

The Preschool Child

Very young children are far more concerned with their fear of pain and dread of separation from their parents than they are with illness or death in general. They are not old enough to understand or worry a great deal about dying. When a child's illness causes a great deal of pain or repeated hospitalization, he or she will be afraid of pain and future hospitalization.

Children who have been hospitalized are frequently afraid of white clothing, which they connect with doctors and nurses who have given them injections and other painful treatments. Today many doctors, nurses, and therapists who work with young children wear ordinary-looking clothes. In the classroom, when reading or talking about doctors or nurses or when role-playing going to the doctor, you should not be surprised if the seriously ill child has some strong reactions.



Understanding of death develops gradually throughout life. For the very young child death has no meaning. Overheard adult conversations, TV or movies, or the death of a pet, begin to create an awareness of dying. Little by little, children begin to understand death, primarily in terms of separation. To little ones, this means being apart from their parents, or the adults who care for them, something they fear greatly since they are so dependent upon adults.

In addition to depending on adults for basic security, the preschool child is extremely sensitive to their feelings and reactions. When adults are depressed, fearful, overly anxious or angry, the child will sense these feelings and react to them. Often the child imitates the adult reactions while playing with dolls or with other children.

Older preschoolers who have experienced a death in the family may still not be too clear about it. But they know that the person is no longer present to play or talk with them. Their awareness of death and separation may show up in their games or drawings. Sometimes preschoolers role-play death and dying or ask questions about death. This can reduce anxiety. When questions are asked, adults should answer in as straightforward and honest a fashion as possible within the child's understanding.

It is not the role of the day-care worker to explain to the child that he or she is dying. This is the role of the parents who must decide how much they want to tell their child. As a day-care worker, you can listen to the children and give them the freedom to express their own views.

The Elementary School Child

As children grow older, they are less protected by adults. The influence of television, movies, books, and other people (children as well as adults) increases. Older children are better able to understand and reason, and they can think in terms of the future. If they do not already know the seriousness of their illness, they rapidly learn. Television specials on cancer, muscular dystrophy, and other medical problems can be understood by the child. And an older child will no doubt realize that he or she has the same or similar disease. Other shows, like soap operas and movies, dramatize illness and death--sometimes unrealistically--and the child can begin to place himself or herself in the role of the dying person. While some shows of this type can help the child understand and accept his or her own particular condition, other shows are hurtful. It is wise for adults to monitor the shows being viewed and to be present to discuss questions the child may have.

Older children become aware of their limitations and their inability to do all the things their friends can do. Physical ability is prized during these years. When the child's illness prevents him or her from physical activity, the teacher, parent or other adult caregiver should find other activities in which the child can participate. For example, the child who cannot run in a game of baseball can sometimes bat or keep score.

As a part of normal mental development, children begin to understand cause-effect relationship during the upper elementary grades. This new ability to understand may not be fully developed, and their reasoning may be distorted when applied to their own illness. They may feel that their illness is caused by something they have done. Some children feel that trips to the hospital and therapeutic treatment are a punishment for their misdeeds. They need assurance that they have not caused their illness in any way.

Elementary grade children not only react and respond to the feelings of the adults around them, as they did in younger years, but they also interpret these feelings. They may feel guilty over causing extra effort on the part of teachers and other caregivers. Those who work with the child should make special efforts to keep the child from feeling that he or she is a burden.

The Teenager

During the pre-teen and teen years, young people normally begin to break away from their parents and other adults as they establish their own identify. Under normal conditions, they pair up with a "best friend" or join with "the group" excluding adults as much as possible from their world. They want to look like and do the same things as their friends.

The young person who is seriously ill is in a bind. Because of the illness, he or she is dependent upon adults, and not free to break away in the same manner as others. By this age the seriously ill child realizes that he or she may not live to become a self-sufficient adult. But in some ways the seriously ill adolescent may be much more mature than others. Often they have spent more time with adults than have other teenagers. And they have had more time to be alone with their own thoughts. They may have had to face the facts of their own mortality, something many adults do not do until well past middle life. In other ways, the ill adolescent may be less mature than others. Extended hospitalization, dependence on adults, and fear of dying may cause the young person to feel and act like a younger child.

And to further complicate matters, seriously ill teenagers may not be accepted by others of the same age. When illness has caused a change in physical appearance, the young person may be rejected by others his or her age. These are years during which appearance is valued. When the young person is disfigured because of illness or necessary treatment, he or she may well be depressed.

In contrast to younger children, teenagers have known life and have planned for the future. As they may feel they are being deprived of their future, anger and hostility is not unusual. Under the best of conditions this can be a very trying age for parents as well as teenagers. When a serious illness is added, sometimes the arguments can seem unbearable.

As with children of other ages, answers to the questions, "Am I going to die?" should be given as honestly as possible. However, the way in which their illness or death is explained is a decision to be made by parents and physicians, not by other adults. As an adult caregiver, you should find out what has been said and how much the young person understands. Follow the lead of the parents in talking with the young person.

Children of various ages respond to the demands of the illness and treatment in different ways, but there are some general problems to prepare for.

THE ROLE OF THE CAREPERSON

It is not easy to deal with your own feelings and attitudes while caring for a seriously ill child, but it is important. In North America today old people often live and die in nursing homes, and almost everyone dies in a hospital. Many of us have had little close experience with serious illness or have been the day to day companion of a dying person. It is not unusual to feel squeamish about the care necessary for a sick person. We are influenced by cultural attitudes and by our own character and previous experience.

Your role as a careperson includes thinking seriously about your own attitudes and feelings, being aware of and dealing with the attitudes and actions of other children, and the day-to-day management of the child within the day-home or center setting. You will also want to be aware of ways of helping the child who is in and out of the hospital. And throughout the entire period of working with a seriously ill child, your contacts with the parents are most important.

Your Feelings

The way you feel will show up in the way you act--what you say, what you do, or what you expect of a child. If someone very close to you has died, you have experienced the feeling of loss caused by death. You may wish to protect yourself from grief, which is quite natural. You may know yourself well enough to realize that developing a close relationship with a child who may soon die might be impossibly painful for you at the present time. You should think through your feelings very carefully. Talking with another person with whom you feel comfortable may help you sort out your feelings. The seriously ill child desperately needs the unconditional love and acceptance of surrounding adults. If, after considering your own feelings and reactions, you realize that you are not the best person to care for the child, then in fairness to the child, let the parents know. On the other hand, your previous experience and your understanding and acceptance of death may make you the ideal person to care for the child. You may be able to give emotional support and strength not only to the child but also to the parents in their time of need. This is a matter which only you can decide.

If you hesitate to accept a part of the care for a seriously ill child, remember that the responsibility is not yours alone. The doctors and the parents are the ones responsible for medical decisions and for talking with the child about his or her illness. Your responsibility is to try to make each hour the child is in your care as productive and happy a time as possible. You do not have to explain medical problems or to make medical decisions. Of course, the more you know about the child's illness the better you'll be able to care for him or her. Talk with the family, or, with the family's permission, speak to the doctor about instructions for physical care. Then be sure to follow the instructions exactly. You may wish to use this checklist of things to do after accepting a seriously ill child into your care:

1. Get emergency telephone numbers (emergency planning is described in Module II--Health Precautions, and Module III--When a Child is Sick or Hurt, of this series)

2. Find out what medication is required. Be sure you have written permission from the parents for giving medication.

3. Find out what emergency symptoms are. Be alert for these symptoms and get help immediately if they occur.

4. Know what actions to take in an emergency. Be sure to review emergency procedures with the parents.

5. Ask if a special diet is required. If so, be sure the child is not served foods which are not on the diet. Children are not always aware of what things they may not eat.

6. Find out to what extent physical activity must be reduced. You may have to think of substitute activities for the child.

7. The child may try to hide symptoms such as exhaustion or coughing in an effort to stay up with the other children. Sometimes you will have to be extra alert to symptoms.

8. Ask if the child is in danger from other children's sniffles, colds, or rashes. Any contagious diesase should be reported to the parents immediately. Childhood diseases which are a minor problem to a healthy child can be a contributing cause of death when a child is already seriously ill.

Working in the Classroom

1. Attitudes of other children

The feelings and attitudes of other children toward the seriously ill child will be shaped by you, the adult responsible for all of the children. The way you act toward the child will be imitated by other children and the warmth and care you give will be recognized. Your explanation of the child's abilities or inabilities to the other children in the center, classroom, or home-care situation will influence the way they react to the child.

The child needs the same give-and-take relationships with other children any normal child requires. There are, however, ome differences which will occur, and you should think about how to handle these most effectively before they become a problem.

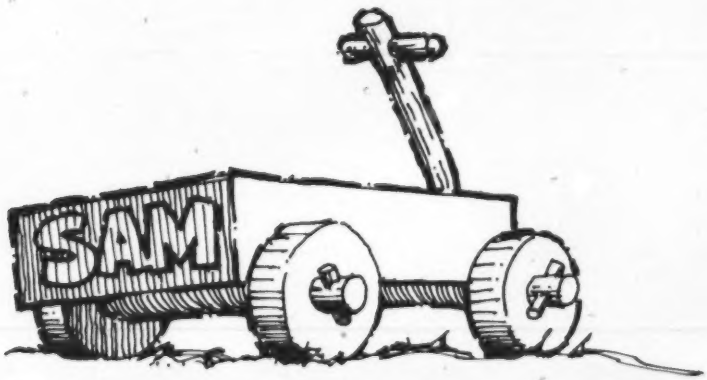
2. Daily routines

Some children may need special medication or treatment during the day. Other children may have to leave the classroom for treatment. Some children who are in and out of the hospital may need to be re-introduced into the daily activities each time they return. These situations automatically set the seriously ill child apart from the other children. You can make these differences seem relatively normal and routine by the way in which you react to them.

If medications are given during the day, do not make a big issue over doing this. Handle it in the way that is easiest for you. You can take the child into the kitchen at certain times and give the medicine, or you can give the medicine wherever the child happens to be. It does not matter. In either case, simply treat the matter as normal routine. When treatment requires changing a dressing, it is best to handle this privately after explaining to the other children that it is time to change the dressing, and that you and the child will return shortly.

Some children may not be able to participate in daily routines such as outdoor play or going on field trips. Substitute indoor activities for the child if he or she is not allowed outside. In other cases, substitute a simpler physical activity on the playground. Let the child be the observer, keep score, or play at a quieter activity which does not require running around. In one situation in which the child was unable to walk to and from the classroom, the teacher suggested a wagon in which to pull the child, and all the children in the classroom took turns pulling the wagon. In another situation the child's eyesight had been severely impaired by illness. The teacher let the children in the classroom take turns helping Mary each day and pretending they were "Mary's eyes." By letting all the children help the ill child, the child will feel more involved in their activities. The other children will also benefit by sharing some of their time and care with the child.

Special routines for the seriously ill child should be explained to all of the children. Remember to keep the explanation simple. Children will accept a simple and to-the-point explanation more easily than a complicated one. Allow the children to ask questions and answer them as honestly as possible. Do not say that the child is dying or discuss the seriousness of the child's illness with the other children. That type of discussion should be left up to the parents.



3. Ugly comments

Children can be cruel to the child who looks different and acts differently. It hurts anyone to hear ugly comments about themselves, and when the child is seriously ill, ugly comments are terribly unfair. Although you cannot protect a child against comments of others completely, by your attitudes and behavior you can prevent some of it. You are the model for the other children to follow. You can:

- Praise the child in front of others. For example, praise any activity that he or she does well and let the child help other children whenever possible. If the child has new glasses, admire them in front of the other children. Sometimes children will have to wear braces or use a wheelchair. You can acknowledge these new things in a positive manner. Explain the use and the purpose of the braces, i.e., to help Sam walk better. By understanding and by setting a model of admiration and respect you will support the child who is ill and influence the other children, too.

- Teach other children how to play with and help the ill child. The seriously ill child, even more than other children, needs warm and friendly relationships. Encourage other children to play with him ar her and help in caring. These activities will help them be more accepting.

4. Discipline

Children who are ill, just like all children, will try the limits which are set by adults. The child who has been ill and hospitalized frequently may have had constant attention and indulgence during this time, which is natural and usually necessary. However, when the child returns to the classroom, it is necessary for him or her to obey the rules and limits just as other children do. There is usually a testing period when the child will try to see just how much he or she can get away with. Do not allow the child to manipulate you or the others with his or her illness or try to draw upon your sympathies to get his or her way. Tempting though it may be to allow the seriously ill child special privileges, and to let the child get by with a little more than others, this is not helpful to the child or to the other children in the classroom. Children can learn to follow one set of rules or guidelines in the classroom setting and a different one in another setting such as the hospital. Children also recognize when one child is being singled out for special treatment. Other children resent that child and even the child who gets special treatment may be resentful of being singled out. Therefore, keep the rules the same to the greatest extent possible for the child who is ill. If changes are necessary in terms of discipline or chores, then explain the reason why to the other children. For example, "Sam does not have to pick up the toys on the playground because he cannot be in the heat. He can pick up the toys inside."

5. Expectations

It is important to have positive attitudes and positive expectations for the child who is ill. Parents may feel as if it is not worthwhile to expect very much of the child since he or she will not live to be an adult. However, this gives the child negative feelings about himself or herself and makes the child feel less competent. Talk with the parents about what they want their child to learn and to do. If their expectations seem too low, explain that you feel the child can learn or do a little more. Then invite the parents into the classroom to observe their child learning these things. For example, Tom's parents saw little point in having him learn to read, since he would not live to use this skill. They sent him to school each day for him to socialize with the other children. The teacher, however, felt that Tom was capable of learning to read and that reading would be a valuable outlet for him, since he was not allowed to participate in any kind of physical activity because of his condition. After talking with the parents and explaining the importance of giving Tom a way to use his active mind, the parents became more supportive of his interest in reading. He became a better reader. The teacher allowed him to read short stories to other children in the class, which helped Tom feel more confident about himself. The other children looked up to and respected Tom because he could read so well.

6. Independence

Encourage the child to be as independent as possible. Often adults are overprotective of the seriously ill child, feeling that the child should not be required to do some of the things that others do. However, the ill child, just like any other child, needs to develop independence. You must, of course, match the independence to the child's ability. But in all cases, give the child as much freedom as possible. For example, for a child who needs help in using the toilet, give the help as needed, but let the child wash and dry his or her own hands afterwards. Of when a child has difficulty feeding himself or herself, simplify the feeding by providing a weighted spoon or by serving finger foods. If the child needs to rest at regular intervals throughout the day, teach the child how to get out his or her own mat to lie on. In this way the child takes care of some of his or her own needs.

Working with the Parents

Be sure to meet with the parents on a regular basis. It is essential for you to be in regular direct contact with them in order to help their child. This does not necessarily mean a formal meeting. You can chat with them about the child's progress, or about future plans for the child's health care, when they bring the child in or pick the child up at the end of the day. In many day-care centers social workers are the primary contact between parents and teachers. However, as the one who works with the child for the greater number of hours during the day, you should talk with the parents yourself and encourage them to visit the classroom. Your direct contact with the parents provides a base for a trusting and cooperative relationship which will help the child.

The child will feel more secure when he or she knows that parents and teachers are working together and that there is continuity between the home and the school. Find out from the parents exactly what has been told the child about the possibility of his or her death. Find out how the doctor is helping the child and other types of help the child may be receiving. Sometimes it is helpful for parents to meet and talk with other parents whose children have died. Although you as a center or classroom teacher should not try to be a counselor, you can help by suggesting the names of other parents with whom this parent might visit.

Parents need to be informed immediately about communicable diseases, accidents, or any unusual behavior on the part of the child. Chicken pox, mumps, measles, or even a simple cold can be immediately life endangering for the seriously ill child. In some cases, accidents are even more serious for the child who is ill than for other children. The seriousness of such things, and the decision whether to see a physician, should be the parents' decision.

Sometimes you may find parents are particularly difficult to work with. Remember, however, that parents have many emotional, physical, and financial drains upon them. Your primary job is to work with the child while he or she is under your care. You can simply be a listening or supporting person to the child.

Sometimes parents will send more equipment, advice, and medications than you can handle. Or the parents may ask you to help the child in ways that are beyond your ability or training. When this happens, talk with your supervisor or center director, and decide how much it is possible to do for the child. Sometimes extra help can be arranged. Other times additional help is not possible. In that case, you and the director or supervisor should meet with the parents to discuss the matter. Decide upon which things are essential and which things are not. Sometimes other resources or persons in the community can provide assistance in terms of therapy or volunteer time in the center or classroom.

HOSPITALIZATION

Effects on the Child

The seriously ill child may require repeated hospitalization. When a child is hospitalized, he or she is isolated from family and friends, as well as from familiar surroundings. This separation, as well as the pain that frequently accompanies treatment, can be most depressing to the young child. If you have a major responsibility for the care of the child as a child-care worker or a teacher, you may actually be with the child more waking hours than the parents. Your visit to the hospital will be greatly appreciated by the child. By visiting the child you can help him or her realize that he or she is not completely separated from the classroom or center. You can keep the child informed about the things that are happening. Even when another teacher or social worker is assigned to the child, it is reassuring to the child to have his or her own teacher visit. Maintaining contact with the child makes it easier to ease the child back into the classroom when the child returns.

Many types of treatment required to prolong life are painful and frightening. X-ray, chemotherapy, and physical therapy, for example, may be of benefit in the long run, but cause the patient a great deal of pain and anguish during the time of treatment. As with adults, extreme pain is not forgotten easily. The very young child does not understand the reason for treatments or why adults are causing such pain.

Children who return to the same hospital for treatments over a period of time begin to realize that other friends they have met there no longer return. They often discover that they have died. This makes the child wonder what will happen to him or her in the future.

Older children may resent and resist treatments which cause them to look different from their friends. One of the hardest problems for older elementary school children and teenagers is the fear of being different. In addition to being limited in physical activities by illness, the side effects of treatment can be humiliating. Drugs used to fight cancer or leukemia have well-known side effects such as loss of hair, gain or loss of weight, or the development of unsightly skin rashes. To the young person who wants to look like his or her friends these problems can be overwhelming. Although there are no easy solutions for these problems, the most important thing is to help the young person realize that <u>you</u> are not influenced by his or her physical appearance.

In the appendix of this manual you will find a summary of information on some illnesses which you may encounter.

How You Can Help

Sometimes children are in and out of the hospital for treatment or surgery, or because their condition has become more serious. Today more parents are deciding to keep their child at home rather than having him or her live the last months or weeks in a hospital. Children are usually miserable in a hospital no matter how kind and competent the staff and surroundings. They are happier when they are with their family and friends in as normal a setting as possible. This also means that they need to have other friends and to see them regularly. As an adult responsible for the care of all children, you can help the seriously ill child as well as the other children by:

. Making and sending cards to the child while he or she is in the hospital.

. Visiting and taking other children to visit the child while he or she is in the hospital. Be sure, however, to check with the parents and with the doctor before taking other children to visit. Be sure that visits are allowed and will not be frightening to the children.

. Assuming a child will get well and return to the day-care center or school. Think positively. Many children do recover or have remissions when least expected.

. Greeting the child warmly when he or she returns to the classroom or center. Let the other children relate what has happened in his or her absence. If a child wants to talk about the hospital stay, let him or her describe it to the others. If the child has had very serious treatment, you may prefer to talk with the child privately before letting the child talk with the other children. Sometimes the child's description of what has occurred might frighten other children in the classroom.

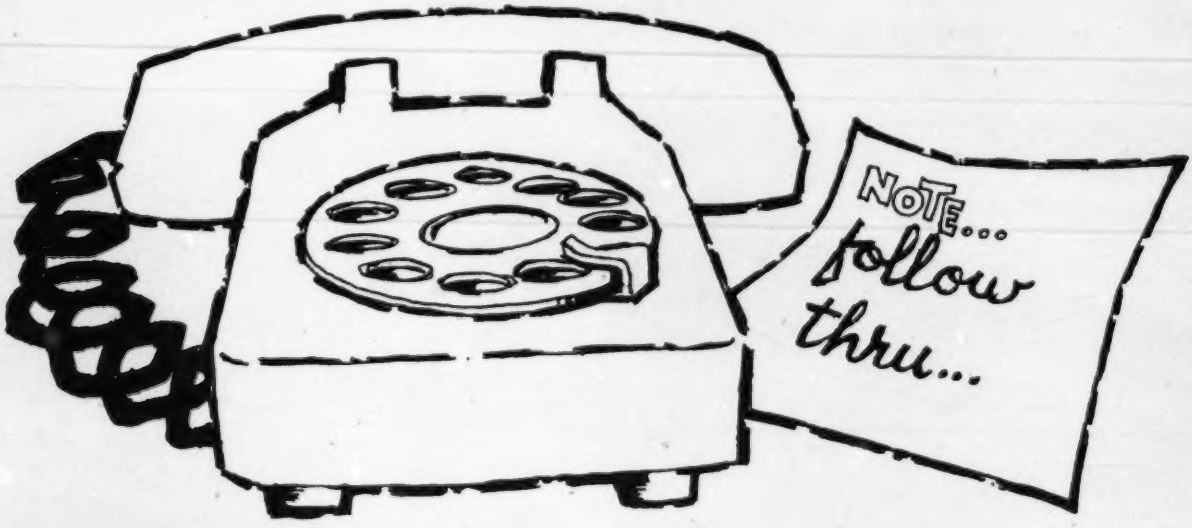
AND AFTERWARDS

Some children will continue to live for some years after they have been under your care as a teacher or home-care worker.

If a child is moving to another classroom or school, talk with the next teacher. After working with a child for a year, you know a great deal about the child and the things he or she can do well. Passing this information along to the next teacher can be most helpful.

Other children will die during the time you have them in your care. No matter how well prepared you may think you are, this will come as a shock. Few words can express the sadness you will feel over the death of a child, even when you realize the child has been in a great deal of pain. Sometimes talking with other teachers or with a counselor will help you with your feelings. If you have cared deeply about the child, you will suffer some of the same grief parents do.

Do not forget the parents, though. If you have been a caring person, visiting with the parents and listening to their concerns while their child was alive, then do not ignore or forget the parents when their child dies. The parents are just beginning to handle the fact of death. Although you should not try to be a counselor, you can go by to see the parents or telephone to ask how they and others are doing.



SUMMARY

If you are now taking care of a seriously ill child, or if in the future you are asked to do so and accept this responsibility, you will have accepted an important challenge. It will require growth and understanding on your part. You may find that you have mixed emotions of your own with which to deal. As a mature adult, you can, however, learn to deal with your feelings and provide some of the emotional support and care needed by the child and his or her parents. You may find, as others have, that you and the parents will develop a strong bond of friendship. You and the parents share the largest part of the child's daily life. Together you are the most important people in the child's world.

During the hours the child is with you, you can help him or her learn to live each hour for the present, without worrying about the past or the future. While doctors are struggling to keep the child alive and parents struggle with their other problems as well as that of losing their child, you can do your best to see that the child's hours in your care are as normal and worry-free as possible. By doing that, you will have contributed greatly in your role as a child-care worker.

APPENDIX

Serious Diseases

There are several types of diseases, some of which occur more frequently than others. Listed below are brief descriptions of some of the more common ones, as well as short descriptions of what you, the child-care worker, should consider in working with the child. Each situation is unique and you should get complete instructions from the child's parents and/or physician to be sure you are meeting the needs of the individual child.

Also, some of these diseases, such as diabetes, can now be controlled, and are life-threatening only when the medical directions are not followed. In the future cures or ways of extending the child's life will probably be found for other diseases as well.

Other problems vary in intensity and may not be life-threatening, although changes or adaptations in the child's daily life may be necessary. For example, some children with heart problems may lead normal lives with a simple reduction in physical activity. For other children, heart conditions will prove fatal.

Cancer/leukemia: Although malignancy in childhood is rare, it is serious and usually life-threatening. As the diseases progresses, body energy goes down and mental ability may be affected. Because cancer is well-publicized, the child may be aware that he or she may die. The child will probably be on medication, including drugs which may cause nausea or vomiting. Chemotherapy may cause loss of hair, weakness, and cause the child to tire easily.

Ask the parents whether the child knows the diagnosis and if so, what the child is being told. You just might be asked. Find out about medication and special needs. Let the child take part in as many activities as possible. Your classroom may provide the child with some of his or her happiest moments.

Sickle Cell Anemia: A hereditary blood disease occuring primarily among black people. No cure has yet been found. As the disease progresses, the person may regress in physical and mental abilities. The child may be tired frequently and need additional rest. The disease is more intense at some times than at others. For periods of time the child may live and learn in a normal fashion.

Cystic Fibrosis: A lung-damaging disease. Recent advances in the treatment of this disease now permit children to live for several years, even into the early adult years. Although physical activities may be restricted, mental or learning abilities are not affected. The child may have dietary restrictions and will probably be on medications. Coughing and frequent trips to the bathroom are common. Catching other childhood diseases can rapidly compound the problem. Parents should be notified immediately when the child is exposed to a communicable disease.

Diabetes: A disturbance in carbohydrate metabolism, diabetes varies in severity. When the child's blood sugar is excessively high or low, he or she may have difficulty in thinking and learning. In some cases diet control is the only treatment while in other cases insulin is necessary. Be sure to check with the parents regarding the child's diet; follow their directions completely. Children, particularly little children, do not understand the importance of what they eat and it is up to the adult to guide them.

Heart Disease: There are many types of heart diseases and problems and great variations in the effects. Unless the problem is severe there is no major effect. In other cases, the child may have to take medication, limit physical activity, or be absent for long periods of time. Check with both the parents and the doctor to be sure of the amount of physical activity allowed. Sometimes children will exhaust themselves trying to keep up with the others, in which case the adult must insist that the child slow down and rest.

Asthma: An allergic condition, asthma affects the lungs, causing a narrowing of the air passageways and difficulty in breathing. The fear of being unable to breathe often causes anxiety in children with asthma. Physical activities may be limited by slowness of breath or fatigue. Encourage the child to participate as much as possible, but don't push him or her. Although asthma itself does not affect the child's ability to learn, in some cases the child may be on medication which slows thinking or reactions. Asthma attacks, when severe, may require emergency care.

Muscular Dystrophy (Duchenne): This is one of several diseases referred to as dystrophies. It is a hereditary disease affecting only males that causes progressive deterioration of the muscles. Sophisticated medical management may extend life expectancy into the twenties or thirties. Treatment now consists of physical and occupational therapy. Influenza and other respiratory infections are particularly dangerous to the child with muscular dystrophy. There are generally no dietary restrictions or medication. Physical activity is increasingly limited as the disease progresses.

In all cases, it is very important to find out exactly the type of treatment or medication needed while the child is under your care. Directions for medication, limitations in physical activities, or dietary instructions should be written down. Any time a child has a serious illness, critical information about the child's daily care should be written down and immediately available. There may be times when you, the child-care worker, are suddenly ill or absent and a substitute may care for the child. Any information which a substitute needs to know should be available immediately.

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